

Written Testimony of  
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Parent of a child with epilepsy in the State of Connecticut

Thank You for the opportunity to submit written testimony regarding Raised HB 5303.

My name is Annemarie Bartlett-Rattell, and I reside in Enfield, Connecticut. I am the mother of a 5-year-old little boy named Tommy. Almost 3 years ago we were blessed with our baby girl, Aislin. We felt like life couldn't get any better than this. We had two beautiful children who were happy and healthy, what more could we want?

Two months later, our son was jumping hard on his bounce-n-spin pony... I was looking at the sales; about to go grocery shopping, when my husband stormed into our bedroom to inform me Tommy was having a seizure. I remember running up and down the hallway, panicking, not knowing where my cell phone was to call 9-1-1 (it had been in my lap when I initially jumped up off the bed). My brother has epilepsy, so I grew up seeing seizures. I'm a registered nurse, so I've dealt with them in my professional life too, and have provided emergency medication administration via IV to stop them. But nothing prepares you for the moment when, your baby is convulsing uncontrollably on the ground; you have no emergency medication, and are helplessly waiting for it to stop and the ambulance to arrive. This first seizure only lasted two minutes. They told us maybe because he had been sick it was a febrile seizure and to just watch him. I remember looking over at my husband as he was driving us home from the hospital that night and saying, "I don't think this is the end of this."

Thirteen days later, Tommy suffered another seizure; I immediately stuck a thermometer in his ear, and just what I had feared, no fever. This time he was in status epilepticus, and it lasted an hour and fifteen minutes. I cringed as I helped the EMT in the back of the ambulance set up the oxygen, and nervously laughing when he pulled out an intubation kit saying "You can put that away, I don't want that out, trying to stay positive over here." Tommy spent the night at the hospital, hallucinating from all the ativan given to make him stop seizing. He kept saying, "Mama, baby sister is cold, she needs a blanket, here, give her mine, she's crying Mama." We left the hospital the following night with his first dose of Keppra circulating in his little beat up body, a medication which we hoped would stop him from ever having one again, and a prescription in hand for emergency medication to be given for any seizure lasting five minutes or greater. He went six months with no seizures, we were nervous but not letting it keep us down.

Then one night we were at our friends' home watching football, all of our kids were playing all around us having a blast. Then Tommy got a blank stare in his eyes, and collapsed into my arms unresponsive and having a full-blown tonic clonic seizure, the emergency medication wasn't in the diaper bag. That was the worst feeling ever. The waiting was the most excruciatingly long period of time ever. This one lasted an hour and a half, requiring several medications to break it, and we found ourselves again overnight at the hospital. His EEG was done inpatient, and was inconclusive due to artifact. This led to him starting preschool at Lego Learning Center later than expected because of his

emergency medication needs. The center jumped through hoops for him to attend, got approval from the Director of Nursing of Connecticut, and changed their corporate policy of medication administration, installed a lockbox for his medication since it is a controlled substance, and trained their staff to administer the medication. They were amazing when his next 2 seizures occurred at their center, and seizures that could have lasted a lot longer were stopped in a more timely fashion (15 minutes or less, sad when you feel like that is "timely.") Each time he had a seizure his keppra was increased and the emergency medication dosage was as well. We were told long term effects of his longest seizures would be unknown until later on, and they did indeed show themselves... He currently suffers from ADHD, Anxiety, Depression, has developed Sensory Integration disorder, as well as some fine motor skill deficits that prevent him from doing things that other children his age can do very easily (such as write their names, button their own clothes, zip zippers, etc.) Despite all he has been through he is a very intelligent, happy, and sweet little boy who wants to learn and play with the other kids. He plays soccer on the town team and has great interest in astronomy and other sciences. His memory is beyond ridiculous!

I was upset when the time came for Tommy to go to kindergarten. Lego, his school that had proved to be the most wonderful place for him offers kindergarten, but I couldn't afford it. My husband had been laid off and was out of work for a long time. So there we were, in the face of public school, scared about the uncertainty of a new staff and new environment, and his safety. We spoke with the school nurse in advance about all of his medications and supplied her with doses of his emergency medication to be kept on hand at the school in case of emergency, and the seizure plan of care was sent to them from Tommy's neurologist. Things were going ok, he enjoyed his orientation before school started and was excited for the new venture!

Two days before his first day of school, he had his first seizure in over fourteen months. We were devastated. He was now on a dose of keppra that was more than some of the doses I was giving to patients at work who were at least ten times his age. The following night he had a partial seizure, which only lasted a little over a minute, and he came out of it on his own. The next day he was not able to attend his first day of kindergarten with all of the rest of the kids. It broke my heart, he had been so excited, and was now filled with disappointment. That was the first time he had ever asked, "what's wrong with me mommy?" My heart sunk and I just told him, you were sick baby, you got very shaky, and weren't responding to Mommy." He didn't understand, "but I'm better now mommy, I don't have a fever! Can I go now?" He had not even been twelve hours seizure-free, so I had to keep him home to make sure he was ok, because he had never had two seizures on two consecutive days before. His first day was everyone else's second day of school, but we still made a big deal of it, so he has that good memory rather than the bitter one of missing it. School was rough in the beginning; Tommy's impulsive behavior and inability to be attentive started the parent-principal-teacher meetings. From that we developed a section 504 plan and are in the process of obtaining an IEP. In the midst of this process I found myself having to strongly advocate and educate, because his school really hasn't had much experience with children with epilepsy and its associated ailments. They didn't understand him it seemed.

We have developed a great relationship with the staff since then and they really want Tommy to be successful like us, but I was rather taken back when his first field trip of his school career came about. I was excited for him when I saw the flyer in his daily folder and immediately signed the permission slips, and filled out the emergency information form. I wrote on the sheets "Please make sure Tommy's emergency medication goes with him on the trip in case of emergency." I did not foresee anything happening since all of his seizures have been in the afternoon and evening before bed. A week passed and we received a phone call from the school nurse asking if one of us would be able to attend as a chaperone. I work night shift and was scheduled to work all the nights surrounding the day trip to the orchard. My father was supposed to be working and my husband has our two-year-old daughter to look after when I am sleeping for work, so we stated that we were unable to attend. The school nurse stated she would find another nurse to go on the trip just in case, to administer his medication if needed. Two weeks had passed; we had heard nothing, so we assumed they had found someone. We received a phone call the afternoon before the field trip day; it was the school nurse stating that she was unable to find a nurse to attend and that if we were unable to go, he would have to stay at school. I was infuriated. I felt like my child was being discriminated against. He was not getting the same educational opportunities as a child who wasn't suffering from epilepsy. How could this be happening??? How could they not provide what he needed? To ensure our son did not miss out on something he was really looking forward to, my father had to go in to work late so he could watch our daughter, and my husband chaperoned on the trip.

I really think the thought of a child being denied the rights that children with no medical conditions are receiving is wrong. Put yourself in his shoes being five years old; would you want to be the only kindergartener sitting in an unfamiliar room, with people you don't know, just wishing you could have fun with your friends? I know I wouldn't. It would make me feel terrible, and I'm an adult who is better able to cope.

We have received several flyers home for after school science programs etc, that we KNOW our son would LOVE to participate in, but we don't always have the ability to be at the school due to our work schedules, and there was no promise a nurse would be in the building for the program times. No other parents have to worry about leaving their child, but we do. If this bill were passed, staff members could be given the necessary training to administer his emergency medication and follow his emergency plan of care, as the school nurse would do. This may also cut down on costs of sending nurses with the children that need them present on a field trip. I fully support this bill for the following reason: if it is passed, children like Tommy would never miss out on educational opportunities just because someone who is "trained" was not there, in case of the unlikely event of something occurring. They would be allowed to interact and enjoy their school experience, and have some semblance of normalcy in the school setting. If it is not passed, my little boy and other children just like him may be left behind, feeling isolated or different. Every child is entitled to the same education, and the same experiences no matter what physical or cognitive disabilities they may have. They suffer enough already; let's not punish them more. Please pass this bill, and leave NO child behind!!!

